Advance Care Planning in North Dakota
The Past ▪ The Present ▪ The Future

Framework
- Dialogue about advance care planning
- “All teach-all learn”
- Interruptions are good . . .
  Your questions and comments!

Questions to Run On
- What is the status of advance care planning in North Dakota?
- How has Honoring Choices North Dakota® (HCND) benefitted from the varied perspectives of its members?
- What is HCND’s advance care planning vision for North Dakota?
- What is your role in improving advance care planning in ND?
Advance Care Planning: Definition

A person-centered, ongoing process of communication that facilitates individuals’ understanding, reflection and discussion of their goals, values and preferences for future healthcare decisions.

Respecting Choices®
Gunderson Health System
http://www.gundersenhealth.org/respecting-choices

Advance Care Planning: Current Status

Sample: Random sample (n = 848,303) of fee-for-service Medicare beneficiaries with diagnosis of cancer, COPD, or dementia in the last 180 days of life

Inpatient: Increased from 62.8% (2005) to 69.3% (2009)

ICU: Increased from 24.3% (2000) to 29.2% (2009)

Hospice: Increased from 21.6% (2000) to 42.2% (2009)

Hospice LOS: Increased short hospice stays (3 days or less) from 22.2% (2000) to 28.4% (2009)

Summary: 80% of Medicare decedents with cancer or COPD hospitalized in last 90 days; 40% with COPD had ICU stay in last month of life

Advance Care Planning: **Current Status**

“In effect, we have created a medical system that treats death as a separate event having nothing to do with life.”

Nora Zamichow whose husband died of an inoperable brain tumor

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What People Say

- **6 of 10** say it is important to talk about wishes for end-of-life care
- **8 of 10** say it is important to have wishes in writing
- **8 of 10** say they would like to talk to their doctor
- **7 of 10** say they would prefer to die at home

What People Do

- **4 of 10** have talked to their loved ones about their wishes
- About **1 in 4** have wishes in writing
- Less than **1 in 10** have had doctor talk to them
- In 2009, about **1 in 3** deaths occurred at home

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Advance Care Planning: No Easy Talk

Perspective: Societal
- Preoccupation with preserving youth and beauty
- Death avoidance
- Death has become unnatural—death removed from our homes
- Medical advancements

Perspective: Individuals/Families
- Don’t want to talk about death
- Culture and ethnicity
- Lack of awareness and importance of ACP
- Not understanding the significance of condition
- Unclear treatment options and decisions
- Family conflict
- No designated health care agent

Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

Advance Care Planning: No Easy Talk

Perspective: Delivery of Person-Centered Care
- Experience multiple transitions near end of life → high rates of preventable hospitalizations
- Increasing demand for family caregiving → personal care, household tasks, medication management → burden
- Delayed referral to palliative care → access


Advance Care Planning: No Easy Talk

Perspective: Clinician-Patient Communication and Advance Care Planning
- Most people near end of life (EOL) unable to make own decisions → advance care planning essential
- People with EOL-care focus on alleviation of pain and suffering → need for medical orders
- Frequent conversations necessary to avoid unwanted treatment → improved ACP communication needs


Advance Care Planning: No Easy Talk

Perspective: Professional Education and Development
- Insufficient attention to palliative care in medical and nursing school curricula → healthcare professionals unprepared
- Educational silos → lack of interprofessional teams
- Deficits in equipping physicians with sufficient communication skills → "the conversation" doesn’t happen

Advance Care Planning: *No Easy Talk*

**Perspective: Policies and Payment**
- Incentives under FFS Medicare → increased use of acute care services and late enrollment in hospice
- Programs integrating health care and long-term services and support → reduce hospitalizations
- Palliative and hospice care → improve patient outcomes and lesson acute care utilization
- Lack of standards and measures → quality??


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**Key Findings: Public Education and Engagement**

- Need for public education and engagement
  
  **National Healthcare Decisions Day**
  
  [http://www.nhdd.org/#welcome](http://www.nhdd.org/#welcome)

- Need to normalize conversations about death
  
  **The Conversation Project**
  
  [http://theconversationproject.org/#](http://theconversationproject.org/#)


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**Percent of Medicare Decedents Hospitalized At Least Once During the Last Six Months of Life Year: 2012; Region Level: HRR**

[Map Image]

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Advance Care Planning: No Easy Talk

“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being.”

Atul Gawande, 2014

*Being Mortal: Medicine and What Matters in the End*
Advance Care Planning: *The History*

- **1991** – Patient Self-Determination Act → ND health care directives authorized
- **1999-2003** – Matters of Life and Death → community forums, end-of-life care education for physicians and nurses
- **2005** – Physician Orders for Life-Sustaining Treatment (POLST) introduced to ND → limited utilization
- **2013** – Inconsistent advance care planning and limited EOL care education for most healthcare professionals

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**Advance Care Planning: The History**

- **April 2013** – QHA (NDHCRI) Advance Care Planning: Beyond an Advance Medical Directive webinar
- **June 2013** – North Dakota Medical Association request
- **August 2014** – North Dakota Advance Care Planning Initiative face-to-face meeting → Honoring Choices North Dakota®
- **December 2014** – HCND Steering Committee formed
- **April 2015** – Honoring Choices North Dakota incorporated as a ND nonprofit organization

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**Honoring Choices North Dakota®**

**Beginning:**
- Conference Call
  - June 2013
  - 12 participating individuals

**Current:**
- Nonprofit Incorporation
  - April 2015
  - 81 members representing 50 associations and organizations from 20 ND communities and 1 from Minnesota

**Perspectives:**
- Physician, nurse practitioner, nurse, social worker, clergy, chaplain, community paramedic, lawyer, higher education, CEO

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Honoring Choices North Dakota®

**Vision**
To create a culture across ND where continuous (ongoing) advance care planning is the standard of care and every individual’s informed preferences for care are documented and upheld

**Goal**
To assist statewide community partners with the development and implementation of a comprehensive advance care planning program by December 2016

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** Objective 1: ** Establish a statewide nonprofit organization to promote advance care planning

**Status:**
Honoring Choices North Dakota® officially organized with Board of Directors April 2015

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<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Location</th>
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<tbody>
<tr>
<td>Judy Beck</td>
<td>Quality Health Associates of North Dakota</td>
<td>Minot</td>
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<tr>
<td>Lynette Dickson</td>
<td>UND Center for Rural Health</td>
<td>Grand Forks</td>
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<tr>
<td>Kathy Evenson</td>
<td>Community Partner</td>
<td>Hillsboro</td>
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<td>Cindy Goehner</td>
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<td>Nancy Joyner</td>
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<td>Courtney Koebele</td>
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<td>Judith Peterson</td>
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<td>Kristin Schlecht</td>
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<tr>
<td>Lori Ustanko</td>
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"The name Honoring Choices North Dakota is used under license from East Metro Medical Society Foundation."
Objective 2: Provide community and professional advance care planning education and outreach
- Training certified ACP Facilitator Instructors who in turn train certified ACP Facilitators

Status:
On behalf of HCND, QHA applied for HRSA Rural Health Care Services Outreach Program Grant to improve ACP → Not awarded

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Objective 3: Develop a process that supports continuous ACP regardless of where individuals receive care
- Advance care planning across care settings within communities and across communities

Status:
WORK IN PROGRESS

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Objective 4: Develop a standardized medical order form that represents an individual’s preferences for end-of-life care

Status:
ND Physician’s Orders for Life Sustaining Treatment (POLST) drafted
WORK IN PROGRESS
Objectives 5: Create a method of communication that makes an individual’s ACP available wherever an individual is provided care

Status: North Dakota Health Information Network

Objective 6: Develop ACP education for:
- a. Health professionals currently in practice
- b. Future health professionals

Status: Work in Progress

Advance Care Planning: And You

Have a conversation with your loved ones.

The Conversation Project

Join Honoring Choices North Dakota® – today!

Spread the word about Honoring Choices North Dakota in your organization – your community.

Contact Sally regarding your interest in a particular objective.

Advance Care Planning: And You

Resources: Website
Great Plains Quality Innovation Network

Great Plains Quality Innovation Network

http://greatplainsqin.org/initiatives/coordination-care/

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Imagine
you’re in a hospital and you can’t speak.

http://www.nhdd.org/#welcome

Honoring Choices North Dakota®: The Conversation

The conversation isn’t about dying . . .
Rather it’s about how you want to live until you die.

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Join the effort!

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